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Samantha Halliday

**Comparative reflections upon the Assisted Dying Bill 2013: a plea for a more European approach**

‘It will generally be found that, as soon as the terrors of life reach the point at which they outweigh the terrors of death, a man will put an end to his life.’

Arthur Schopenhauer<sup>1</sup>

**Introduction**

The 21<sup>st</sup> century has witnessed a trend towards legislating to permit assisted dying in the United States of America and within Europe, although the scope of the legislation and regulatory models adopted vary considerably between the two continents. Thus physician assisted suicide is regulated by statute in Oregon (Death With Dignity Act 1997), Washington (Death With Dignity Act 2008) and Vermont (Patient Choice and Control at End of Life Act, 2013), whilst active voluntary euthanasia and physician assisted suicide are regulated by statute in the Netherlands (Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2001) Belgium (Law Relating to Euthanasia, 2002)<sup>2</sup> and Luxemburg (Law of 16 March 2009 on Euthanasia and Assisted Suicide, 2009).<sup>3</sup> In England and Wales

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<sup>1</sup> Arthur Schopenhauer ‘On suicide,’ in *Studies in Pessimism*, trans T. Bailey Saunders Nework: Cosimo, 2007, at 28.

<sup>2</sup> Although Art. 2 Belgian Act defines euthanasia as ‘the act, performed by a third party, which intentionally ends the life of a person at his or her the request,’ a definition that clearly excludes assisted suicide, the Belgian FCCE has taken the view that the Belgian Act applies to PAS as well as euthanasia, reasoning that the Act does not say how euthanasia should occur. Federale Controle – en Evaluatiecommissie *Euthanasie Eerste Verslag Aan de Wetgevende Kamers 22 september 2002 - 31 december 2003* [First report of the Federal Commission of Evaluation and Control Committee], 2004, at 24.

<sup>3</sup> In Switzerland Art. 114 Penal Code prohibits AVE, but assisting suicide does not constitute a crime unless the assistance is rendered for a selfish reason, Art.115 Penal Code. This article will not consider the practice of assisted suicide in Switzerland as it is practiced in a legal vacuum without effective regulatory control.

assisted dying<sup>4</sup> remains topical, not least due to the steady stream of cases considered by the courts where individuals have sought to challenge the absolute prohibition of assistance that currently applies.<sup>5</sup> The courts have long recognised the need for Parliament to consider end-of-life decision-making, consistently noting that any repeal of the prohibition must be undertaken by the legislature rather than by judicial creativity.<sup>6</sup> Nevertheless, a number of courts and committees have concluded that legalisation should not occur, a recommendation based not only on a concern to uphold the sanctity of life, but also due to the perception that it would simply not be possible to legalise assisted dying whilst incorporating sufficient safeguards within the legislation to protect the vulnerable.<sup>7</sup> The latest Bill to seek to legalise assisted dying in England and Wales is Lord Falconer's Assisted Dying Bill 2013, a Private Member's Bill designed to legalise physician assisted suicide (PAS) for the terminally ill.<sup>8</sup>

This article assesses the validity of the argument that the inherent problems of legalisation are insurmountable by evaluating the safeguards incorporated into the Assisted Dying Bill 2013 and reflecting upon the experience of the statutory regulation of assisted dying in three other jurisdictions: the Netherlands and Belgium, representing the European model of regulation, and Oregon, illustrating the American approach to regulating assisted dying.<sup>9</sup> Part one of this

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<sup>4</sup> Assisted dying is used in varying contexts to refer to only PAS (as in the case of the Assisted Dying Bill 2013), or to encompass both PAS and AVE. Throughout this article reference to assisted dying should be taken to include either or both forms of assistance, unless otherwise indicated. As discussed below, the form taken by assistance is of little import see below at 000.

<sup>5</sup> See for example *R (Pretty) v Director of Public Prosecutions* [2002] 1 AC 800; *Pretty v UK* (2002) 35 EHRR 1; *R (Purdy) v Director of Public Prosecutions* [2009] UKHL 45, [2010] AC 345; *Nicklinson v Ministry of Justice* [2012] HRLR. 16, [2012] EWHC 304 (QB), *R (Nicklinson and another) v Ministry of Justice R (AM) v Director of Public Prosecutions* [2013] EWCA Civ 961; [2013] WLR (D) 326.

<sup>6</sup> See for example *Airedale NHS Trust v Bland*, [1993] A.C. 789, per Lord Mustill at 891, *Pretty* n.5 per Lord Steyn at 834, per Lord Hobhouse at 852, *R v Inglis* [2010] EWCA Crim 2637, [2011] 1 WLR 1110, per Lord Judge CJ at [39], *Nicklinson* n.5, per Toulson LJ at [74ff.] (QB), and Lord Dyson MR and Elias LJ at [60] (CA).

<sup>7</sup> See for example *House of Lords Select Committee on Medical Ethics*, HL paper 21 (1993-4), hereinafter HL SC 1993; New York State Task Force on Life and the Law, *When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context* (New York, NYSTF, 1994) ix; *Washington v Glucksburg* 521 US 702, per Rehnquist CJ at 731-2 (1997).

<sup>8</sup> The first reading of the Assisted Dying Bill 2013 took place on 15 May 2013. At the time of writing, the second reading has not yet been scheduled.

<sup>9</sup> Space precludes a detailed consideration of each of the jurisdictions, however the Vermont and Washington Acts are closely modelled on the Oregon DWDA and the Luxemburg Act is heavily derived from the Belgian

article briefly outlines the context within which end-of-life decision-making takes place and considers the way in which the principle of dignity has been asserted by both proponents and opponents of legalisation. Thus it may be asserted to demand that a person has a right to die with dignity, where dignity is constructed as entailing a choice to die with medical assistance. Alternatively it may require that the prohibition of assisted dying be maintained in order to ensure the dignity of the person, regardless of whether that person is disabled or terminally ill. Thereafter, part two outlines the regulatory schemes adopted to permit assisted dying in other jurisdictions before critically considering the provisions of the Assisted Dying Bill 2013, assessing the key substantive and procedural safeguards set out therein and comparing them to those set out in the European and American Acts.

Any legislation enacted must attain a balance between instituting a rigorous system of control mechanisms to ensure compliance and accountability, whilst simultaneously ensuring that the safeguards and procedures do not become so onerous as to defeat the objective of the legislation, to enable the provision of assisted dying in qualifying cases. In seeking to achieve this balance it is argued that we can learn much from the experiences of other jurisdictions, both in terms of what safeguards have been demonstrated to ensure quality and accountability in decision-making, whilst also identifying those which appear to serve no useful purpose. It would however be a misconception to believe that laws can simply be transplanted from one jurisdiction to another, although arguably that is what the Assisted Dying Bill 2013 attempts to do, taking the Oregon Death with Dignity Act and seeking to import it almost wholesale into the very different legal, social and cultural context that exists in England and Wales. Significant differences exist between the way in which end-of-life care, and health care in general, are provided, not least the fact that Oregon, along with the rest of the USA, does not offer universal healthcare. Therefore, it is suggested that policy

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Act, with the only significant difference being that it makes no provision for a minor to request assistance in dying.

makers in England and Wales should give much greater consideration to the European model of regulation which operates in a social and political context much closer to our own.

It will be concluded that it is possible to construct legislation authorising assisted dying in strictly controlled circumstances, without undermining the prohibition of intentional killing, described by the Walton Committee as ‘the cornerstone of law and social relationships.’<sup>10</sup> Moreover, it will be argued that far from exposing the vulnerable to the risk of abuse, such regulation would provide much greater protection of all lives than the current law that ensures end-of-life decision-making takes place in a twilight zone of obfuscation, where foreseeable consequences are divorced from intention and resort is made to dubious distinctions drawn between acts and omissions, without any safeguards designed to ensure patient safety or medical accountability.

## **I The context of end-of-life decision-making and the construction of dignity**

### **A The context**

In the majority of cases death is now medically managed, that is death has been medicalised to the extent that when, where and how we die is increasingly a medical decision. Each of the jurisdictions recognise that a patient with capacity has the right to refuse medical treatment, even life-sustaining treatment, contemporaneously or in advance through an advance decision/directive<sup>11</sup> and that doctors acting in contravention of that refusal will commit a trespass to the person.<sup>12</sup> Absent such a treatment refusal, the courts in each jurisdiction have recognised that doctors may lawfully withhold or withdraw life-sustaining

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<sup>10</sup>HL SC 1993, n. 7. at para.237.

<sup>11</sup> *In Re T. (Adult: Refusal of Treatment)* [1993] Fam. 95, per Lord Donaldson MR at 102; *Bland*, n.6, per Lord Keith at 857; *St George's Healthcare NHS Trust v S* [1998] 3 All ER 673, per Judge LJ at 685; *Re MB (Medical Treatment)* [1997] 2 F.L.R. 426, per Butler-Sloss LJ at 432; s.24 Mental Capacity Act; Article 450 Dutch Civil Code; Article 8 §4 Belgian Law Relating to the Rights of the Patient, 2002; *Cruzan v Director, Missouri Department of Health* 497 U.S. 261 (1990).

<sup>12</sup> *In Re T.* n.11, per Lord Donaldson MR at 102; *Bland* n.6, per Lord Mustill at 891; *B v An NHS Hospital Trust* [2002] 2 All E.R. 449; *Cruzan* n.11

medical treatment, such non-treatment decisions being classified as legally innocuous omissions, rather than active intervention to terminate life. Moreover, a non-treatment decision (to withhold artificial nutrition and hydration) may be combined with sedation until death occurs, a procedure variously termed terminal sedation, or palliative sedation.

Similarly, the courts have accepted the dubious construction of intention afforded by the doctrine of double effect, whereby a doctor may administer pain-relieving medication with the intention of alleviating pain, despite recognising that it is also likely to hasten the patient's death.<sup>13</sup> The tenability of the doctrine has been wholly undermined by both the House of Lords' decision in *R v Woollin*<sup>14</sup> that conflated foresight with intention and by increased knowledge about the functioning of opioids. Clinical evidence demonstrates that 'reasonable' use of opioids will not hasten death,<sup>15</sup> instead a very large increase in the dosage, larger than could possibly be thought necessary to relieve pain, will be required to achieve that effect, something that will not be compatible with an intention to merely relieve pain.

The spurious nature of the difference between actively causing death and merely omitting to treat, together with the dubious nature of the doctrine of double effect, have undoubtedly left the law 'morally and intellectually misshapen.'<sup>16</sup> Nevertheless, English law maintains its absolute prohibition of intentional killing, categorising the active termination of life at the patient's request as murder. In contrast, both the Dutch and the Belgian Parliaments enacted legislation more than a decade ago allowing doctors to perform active voluntary euthanasia

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<sup>13</sup> *Bland* n. 6, per Lord Goff at 868; *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33, per Lord Donaldson at 46; *R v Adams* H. Palmer, 'Dr Adams' Trial for Murder' [1957] *Crim LR* 365, per Devlin J.

<sup>14</sup> [1999] 1 AC 82, at 93, per Lord Steyn.

<sup>15</sup> See for example D. Azoulay et al. "Opioids, survival, and advanced cancer in the hospice setting" (2011) 12 *Journal of the American Medical Directors Association* 129, RK Portenoy et al. "Opioid use and survival at the end of life: a survey of a hospice population." (2006) 32 *Journal of Pain and Symptom Management* 532, B. Estfan et al. "Respiratory function during parenteral opioid titration for cancer pain." (2007) 21 *Palliative Medicine* 81.

<sup>16</sup> *Bland*, n. 6, at 887.

(AVE) in certain circumstances without incurring criminal liability. Moreover, whilst legislation enabling doctors to assist suicide has been enacted in the Netherlands and Oregon,<sup>17</sup> in England and Wales such assistance is prohibited by s.2 Suicide Act 1961. Prosecutions under s.2 may only be instituted with the consent of the Director of Public Prosecutions, but the guidance issued in the wake of the House of Lords' decision in *R (Purdy) v Director of Public Prosecutions*<sup>18</sup> suggests that 'professional' assisted suicide will not be tolerated, listing the fact that 'the suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional [or] a professional carer' as a public interest factor in favour of prosecution.<sup>19</sup> Requiring the DPP to give guidance as to the relative weighting of this factor, the majority of the Court of Appeal recently recognised that as it currently stands the guidance does not enable a healthcare professional to foresee to a reasonable degree the consequences of providing assistance, thus breaching Art. 8(2) ECHR.<sup>20</sup> The policy does not indicate whether the fact that the assistor was acting in her capacity as a healthcare professional might be outweighed by factors identified as tending against prosecution, including for example that the patient 'had reached a voluntary, clear, settled and informed decision to commit suicide' (para.45(1)); the assistor 'was wholly motivated by compassion' (para.45(2)); and that she reported the assisted suicide to the police and fully assisted them in their enquiries (para.45(6)). The DPP has sought leave to appeal to the Supreme Court, but any clarification ultimately issued may be that the fact that assistance was provided by a healthcare professional is the overriding consideration, further deterring healthcare professionals from openly assisting suicide.

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<sup>17</sup> The FCCE has concluded that the Belgian Act does apply to PAS, notwithstanding the fact that it refers only to euthanasia (Art. 2), n.2.

<sup>18</sup>N.5.

<sup>19</sup> *DPP, Policy for Prosecutors in respect of Cases of Assisted Suicide*, 2010, para. 43(14), available at [http://www.cps.gov.uk/publications/prosecution/assisted\\_suicide\\_policy.pdf](http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.pdf).

<sup>20</sup> *Nicklinson* n.5 at [140].

It is submitted that prosecutorial policy is a blunt and inappropriate tool for regulating assisted dying, a task that should be left to the legislature. In a small number of cases doctors assist their patients to commit suicide or actively terminate patients' lives, in some cases without a request from the patient. Significantly, studies demonstrate that this final category of end-of-life decisions is not limited to jurisdictions where assisted dying is legally permissible, with Clive Seale reporting that from 2007-8 0.21% of all deaths in England and Wales were cases of AVE.<sup>21</sup> The absolute prohibition of assisted dying means that end-of-life decision-making takes place in the twilight zone; doctors undoubtedly do assist dying, but they do so in secret, without recourse to structures intended to support their decision-making, such as a second opinion, or to ensure that the assistance is rendered on the basis of the patient's free and informed request. The time has come to address the issue, rather than to continue to allow the law and policy pertaining to end-of-life decision-making to continue to develop in a fragmented manner.

## **B. The principle of dignity and assisted dying**

The concept of dignity has become increasingly important in discussions about death and the process of dying, as the European Court of Human Rights recognised, human dignity and human freedom form 'the very essence of the Convention.'<sup>22</sup> However, despite frequent reference to the notion in international instruments, there is no consensus upon what is meant by 'dignity' in this, or other medical contexts.<sup>23</sup> Recognising that it can be used as both a sword and a shield, Deryck Beylvelde and Roger Brownsword offer two constructions of dignity, namely dignity as empowerment and dignity as constraint.<sup>24</sup>

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<sup>21</sup> C. Seale "End-of-life decisions in the UK involving medical practitioners" (2009) 23 *Palliat Med* 198.

<sup>22</sup> *Pretty v UK* n.5, at para 65.

<sup>23</sup> See, for example the multiple understandings of dignity adopted by contributors to ED Pellegrino et al (eds.), *Human Dignity and Bioethics* Notre Dame: University of Notre Dame Press, 2009.

<sup>24</sup> D. Beylvelde & R. Brownsword *Human Dignity in Bioethics and Biolaw*, Oxford: OUP, 2001.



Conceptualising dignity as empowerment recognises the manner in which it can be used to support choice, to reinforce autonomy. It is this construction of dignity that has been adopted by those seeking to promote assisted dying who use it as a more publicly acceptable synonym for autonomy. Thus the right to die movement no longer campaign for ‘euthanasia’, or even ‘assisted suicide’ preferring to talk of ‘dignity in dying’ or ‘assisted dying’, whilst emphasising that they are motivated by compassion and choice. Both formulations are well demonstrated by the renaming of the main right to die organisations on both sides of the Atlantic - the British Voluntary Euthanasia Society renamed itself ‘Dignity in Dying’, whilst its American counterpart became ‘Compassion and Choices’. Similarly, the titles given to the American Acts (the ‘Death with Dignity Acts’ of Oregon and Washington, and Vermont’s ‘Patient Choice at End of Life Act’) demonstrate the key role now attributed to dignity as a vehicle for choice, even though, as Susan Behuniak notes, none of the Acts make any attempt to define ‘dignity’.<sup>25</sup>

The synthesis of dignity with autonomy can also be observed in the judicial consideration of end-of-life decision-making. Thus, for example, in *Cruzan*, an American case concerning the withdrawal of artificial nutrition and hydration from a woman in a persistent vegetative state, Justice Brennan (dissenting) held that Nancy Cruzan was ‘entitled to choose to die with dignity.’<sup>26</sup> He reached this conclusion notwithstanding the fact that she was in a persistent vegetative state and thus incapable of formulating any choice other than that made by a third party on her behalf through the application of substituted judgement! Moreover, dignity as empowerment formed the basis of the successful challenge to Montana’s prohibition of assisted suicide in *Baxter v. Montana* (2009).<sup>27</sup> Relying on article 2(4) Montana Constitution (‘The dignity of the human being is inviolable...’) Mr Baxter sought to use dignity to

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<sup>25</sup> S. Behuniak “‘Death with “dignity”’: The wedge that divides the disability rights movement from the right to die movement’ (2011) 30(1) *Politics and the Life Sciences* 17, at 19.

<sup>26</sup> *Cruzan* n.11, at 257.

<sup>27</sup> 224 P.3d 1211 (2009).

reinforce his claim to autonomy, to be able to decide for himself, together with his doctor, when the time had come to die. In the District Court Judge McCarter concluded that:

The right to personal autonomy included in the state constitutional right to privacy, and the right to determine ‘the most fundamental question of life’ inherent in the state right to dignity, mandate that a competent, terminally ill patient has the right to choose to end his or her life.<sup>28</sup>

This construction of the concept of dignity, focussed upon personal choice, is consistent with that adopted by the US Supreme Court in its abortion jurisprudence. Writing for the majority in *Casey*, Justice O’Connor expressed this notion in the following terms:

These matters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State.<sup>29</sup>

Application of such a formulation of dignity, based upon autonomy and the construction of personhood through choices, requires that our death or dying reflects the choices we made about how to live, about what was important to us, and this construction was echoed in the approach taken by Lord Justice Hoffmann in *Bland*, where he stated that:

It is demeaning to the human spirit to say that, being unconscious, he can have no interest in his personal privacy and dignity, in how he lives or dies. Anthony Bland therefore has a recognisable interest in the manner of his life and death which can

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<sup>28</sup> *Baxter v Montana*, December 5, 2008; 2008 *Mont. Dist.* LEXIS 482. On appeal The Montana Supreme Court affirmed the District Court’s decision, but on other grounds.

<sup>29</sup> *Planned Parenthood of Southeastern Pennsylvania et al v Casey* 505 US 833 (1992), at 851.

help the court to apply the principles of self-determination and the value of the individual.<sup>30</sup>

In making this argument Lord Justice Hoffman relied on Ronald Dworkin's distinction between critical and experiential interests, arguing that critical interests will survive incapacity, that our interest in the manner in which we live and die will survive even a persistent vegetative state.<sup>31</sup> Thus this conception of dignity as empowerment seeks 'to reinforce claims to self-determination rather than to limit free choice.'<sup>32</sup> It is subjective and prioritises the values of the individual, rather than seeking to establish a universal human dignity.

The construct of dignity as empowerment is clearly expressed in the reasons given for seeking assisted dying. Those reasons demonstrate that pain is not the only, or even the principal, source of suffering, rather individuals seeking assistance are generally motivated by a desire to retain, or indeed regain control of their lives. Thus in Oregon, the most common concern relating to end-of-life has consistently been reported as 'losing autonomy' (93.5% of PAS recipients), followed by being 'less able to engage in activities making life enjoyable (92.2%) and loss of dignity (77.9%), contrasted with 'inadequate pain control or concern about it' (29.9%).<sup>33</sup> As these reasons highlight, the availability of assisted dying may promote the individual's dignity, empowering her to determine not only the timing, but also the manner of her death and reflecting Nietzsche's proclamation: 'I want to die proudly when it is no longer possible to live proudly'.<sup>34</sup>

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<sup>30</sup> *Bland*, n. 6, at 829.

<sup>31</sup> R. Dworkin *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (London: Harper Collins, 1993, 199ff.

<sup>32</sup> D. Beyleveld & R. Brownsword n.24, at 28.

<sup>33</sup> Oregon DWDA Annual Report 2012, at 5.

<sup>34</sup> F. Nietzsche "The Twilight of the Idols" in *The Complete Works of Friedrich Nietzsche (1909 – 11)*, vol. 16, at 88.

A subjective conceptualisation of dignity supports the position that individuals should be able to determine at what point their suffering becomes unbearable, to the extent that they wish to be assisted to die; it focuses upon the individual and the values she holds. However, there are multiple understandings of dignity, and as Beyleveld and Brownsword recognise it can also be used to enforce paternalism, to protect the dignity of all humans by denying individual choice. This concept of human dignity as constraint underlies much of the stated opposition to legalising assisted dying, namely that such a course would negatively impact upon the social perceptions of disability and would devalue the lives of the most vulnerable members of society, particularly the elderly, the sick and the disabled. The Walton Committee recognised this danger, concluding that ‘the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death, but should assure them of our care and support in life.’<sup>35</sup>

As Susan Behuniak has argued, ‘the debate over physician assisted death occurs within a cultural context that assumes the indignity of life with a disability.’<sup>36</sup> Thus, the most vocal opponents to the legalisation of assisted dying have been disability rights campaigners, arguing that any step on the road to legalisation risks degrading the lives of the disabled, that the talk of ‘right to die’ might become a ‘duty to die’.<sup>37</sup> Using dignity as constraint, it is argued that the dignity of all people can only be protected if the absolute prohibition of intentional killing is maintained, that any step towards legalisation of assisted dying will be a step down the slippery slope to non-voluntary and even involuntary euthanasia.<sup>38</sup>

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<sup>35</sup> *HL SC 1993*, at para.239.

<sup>36</sup> S. Behuniak ‘“Death with “dignity”: The wedge that divides the disability rights movement from the right to die movement’ (2011) 30(1) *Politics and the Life Sciences* 17, at 25.

<sup>37</sup> See for example Jane Campbell, ‘It’s My Life—It’s My Decision? Assisted Dying Versus Assisted Living’ in Luke Clements and Janet Read (eds), *Disabled People and the Right to Life* (Routledge, 2008) 85.

<sup>38</sup> Space precludes a detailed consideration of the slippery slope argument in both its logical and empirical forms, suffice it to say that studies conducted in the Netherlands, Belgium and Oregon have found no evidence of a slippery slope. For an excellent account of the slippery slope argument see S.W.Smith *End-of-Life Decisions in Medical Care*, Cambridge: CUP, 2012, chapter 13; S. W. Smith, ‘Fallacies of the Logical Slippery Slope in the

The evidence of those jurisdictions where assistance is lawfully available needs to be assessed in order to evaluate how credible a threat the legalisation of assisted dying poses to vulnerable groups. Detailed studies have been conducted in the Netherlands, Belgium and Oregon; there is no evidence of a systemic risk to members of vulnerable groups.<sup>39</sup> Indeed, as Margaret Battin noted ‘people who died with a physician’s assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges.’<sup>40</sup> Similar findings have been reported by Judith Rietjens and Yanna Van Wesemael indicating that those belonging to vulnerable groups may suffer discrimination, finding it very difficult to access assistance in dying, rather than being coerced into requesting such assistance.<sup>41</sup>

As Roger Brownsword recognises, the argument concerning the inability to protect the vulnerable is a ‘one-sided precautionary argument.’<sup>42</sup> In framing safeguards it is important to take account of the constituents of that group which might be considered the most vulnerable in any debate about assisted dying – the disabled, and to involve constituents of this group in the framing of safeguards. However, it is also important to note that whilst disability campaign groups tend to oppose the legalisation of assisted dying, the same is not necessarily true of disabled individuals,<sup>43</sup> thus 75% of people with a disability surveyed for the British

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Debate on Physician-Assisted Suicide and Euthanasia’ (2005) 13 *Medical Law Review* 224; cf. J. Keown, *Euthanasia, Ethics and Public Policy: an Argument Against Legalisation*, Cambridge: CUP, 2002, chapter 7.

<sup>39</sup> See for example F. Norwood et al “Vulnerability and the ‘slippery slope’ at the end of life: a qualitative study of euthanasia, general practice and home death in the Netherlands” (2009) 26(6) *Fam Pract* 472; M. Battin et al “Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ‘vulnerable’ groups” (2007) 33 *JME* 591; Y. Van Wesemael et al., “Process and Outcomes of Euthanasia Requests under the Belgian Act on Euthanasia: A Nationwide Survey”, (2011) 42(5) *J Pain Symptom Management* 721, J.A.C. Rietjens et al “Medical end-of-life decisions: Does its use differ in vulnerable patient groups? A systematic review and meta-analysis” (2012) 74 *Social Science & Medicine* 1282

<sup>40</sup> M. Battin et al n 39, at 597. Cf I.G.Finlay & R.George “Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups – another perspective on Oregon’s data” (2011) 37 *JME* 171.

<sup>41</sup> Y. Van Wesemael et al., n 39; J.A.C. Rietjens et al n. 39.

<sup>42</sup> R. Brownsword et al “Prospective Legal Immunity and Assistance with Dying: Submission to the Commission on Assisted Dying” (2012) 23 *KLJ* 181, at 185.

<sup>43</sup> Pamela Fadem et al, ‘Attitudes of People with Disabilities towards Physician-Assisted Suicide Legislation: Broadening the Dialogue’ (2003) 28(6) *Journal of Health Politics, Policy and Law* 977; Charles E Drum et al,

Social Attitudes study in 2005 were found to support the legalisation of assisted dying,<sup>44</sup> and all the legal challenges to the prohibition of assisted dying have involved profoundly disabled individuals seeking assistance in dying.<sup>45</sup> Moreover, the fear that the vulnerable might feel obliged to take part in assisted suicide does not mean that this area should fall outside the regulatory landscape, rather it provides good reason to regulate and to ensure that a robust system of regulation can negate such coercion, to ensure that assessments of an individual's quality of life are made by that individual herself and not by a third party.

Thus it is suggested that this one-sided precautionary model fails to distinguish between instances where the disabled person's autonomy is undermined (when a third party makes a decision that for example she should not be resuscitated) and those where a disabled individual exercises autonomy, for example by choosing to refuse treatment or to request euthanasia. It fails to recognise both the plurality of opinions within the various communities that could be considered vulnerable and that, as the evidence shows, members of those communities may find it more difficult, rather than less, to access assistance in dying.

Susan Behuniak summarised the difference between the competing formulations of dignity in end-of-life decision-making as being that for proponents of assisted dying, dignity determines how one dies, whilst opponents fear the principle of dignity may be used to determine who should die.<sup>46</sup> It is suggested that a more nuanced understanding of the concept may enable the recognition of both the personal and broader concepts of dignity in a system within which assisted dying is legal, through the creation of a robust framework of strong procedural and substantive safeguards. The creation of such a framework would recognise the inherent value of all life and give effect to the state's duty to protect life, but simultaneously recognise the

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'The Oregon Death with Dignity Act: Results of a Literature Review and Naturalistic Inquiry' (2010) 3 *Disability and Health Journal* 3.

<sup>44</sup> E. Clery et al "Quickening Death: the Euthanasia Debate" in Park et al (eds) *British Social Attitudes: 2006 – 2007, The 23<sup>rd</sup> Report*, London: Sage 2007.

<sup>45</sup> See for example the cases brought by Diane Pretty, Debbie Purdy and Tony Nicklinson, n.5.

<sup>46</sup> S. Behuniak n.36, at 28.

dignity of individuals in permitting them to choose to be assisted to die, subject to satisfying the safeguards designed to ensure that assistance is only provided in the case of a competent, free choice. Moreover, it will be argued that such a choice can only be made in the context of comprehensive social and palliative care, necessitating an investment in both.

Whilst there is a need to protect the vulnerable, there is also a need to respect the right of everyone to choose for themselves what constitutes an acceptable quality of life. Permitting an individual to choose to be assisted to die should not undermine respect for the disabled in general, indeed by creating strong and effective regulation of assisted dying the legislation should form a bulwark protecting all life, disabled or otherwise, against quality of life evaluations made by a third party, respecting the inherent dignity of all life. Diane Coleman, the president of Not Dead Yet, locates the group's opposition to assisted dying in the experience of disabled people within the broader healthcare system arguing that 'As society's proverbial "canaries" in the health care system, disability rights advocates are sounding the alarm against granting legal immunity to physicians for assisted suicide based on our experiences in the front lines of that system.'<sup>47</sup> As Coleman suggests, other end-of-life decisions, whether they be non-treatment decisions, or aggressive alleviation of pain, may be disproportionately aimed at the vulnerable; however, it important to recognise that unlike assisted dying such decisions do not require the patient to make a voluntary request for assistance, the cornerstone of any assisted dying legislation. There is a need for clarity about the whole gamut of end-of-life decisions, about the status of pain relief and palliative sedation, and about the basis for the distinction between acts and omissions. The Assisted Dying Bill 2013 offers the opportunity for Parliament to consider this area once again, but as

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<sup>47</sup> D. Coleman "Assisted suicide laws create discriminatory double standard for who gets suicide prevention and who gets suicide assistance: Not Dead Yet Responds to Autonomy, Inc." (2010) 3 *Disability and Health Journal* 39, at 49.

will be discussed below it fails to set out a sound procedural framework for end-of-life decision-making.

## **II Comparative reflections upon legislation permitting assisted dying**

### **A An overview of the European and American Regulatory Models**

The European regulatory model applies to both euthanasia<sup>48</sup> and PAS and is based upon fulfilment of the due care criteria, followed by reporting to a monitoring commission. The primary due care criteria set out in the European Acts are that: the patient made a voluntary and carefully considered request; the patient was suffering unbearably without prospect of improvement; the attending doctor informed the patient about his situation and his prospects and, together with the patient, concluded that there is no reasonable alternative to assisted dying; the attending doctor must have consulted at least one other, independent physician. A key feature of the European regulatory model is the use of a monitoring commission to ensure compliance with the legislation and assess the operation of the law in this area; as will be discussed below, no similar regulatory body is found in the American model of regulation. Moreover, the European model differs from its American counterpart by requiring that the individual be suffering unbearably, but not necessarily that the individual be terminally ill, and by making provision for anticipatory requests for euthanasia to be made in advance of incapacity and for requests by minors.

By contrast the American model of regulation is limited to PAS and requires that the patient be terminally ill, defined as suffering from an ‘incurable and irreversible disease that ... will, within reasonable medical judgment, produce death within six months.’<sup>49</sup> The American

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<sup>48</sup> Throughout this article when reference to the Dutch and Belgian law is made, ‘euthanasia’ will be used in the Dutch/Belgian sense, that is in relation to the active termination of an individual’s life at her request, categorised as AVE in the Anglo-American literature.

<sup>49</sup> Oregon Death With Dignity Act s.1(12); cf. Washington Death With Dignity Act RCW 70.245.010 (13); cf. Vermont Patient Choice at End of Life Act § 5281 (10).



Acts do not require that the patient be suffering unbearably, or that euthanasia be a last resort, but the remaining due care requirements found in the European model are also found in the American legislation (the need for a voluntary, informed request and a second opinion), with the addition of a cooling off period applied in all cases. Unlike the European model of regulation, no provision is made for the creation of a regulatory body to ensure compliance with the Act. Instead, doctors are required to maintain records detailing compliance and to report the assistance to the Health Authority. The function of the authority is very different from that of the European monitoring commission, its primary role being to compile and publish an annual statistical report concerning the Act, rather than to monitor compliance with the Act and evaluate its operation. A detailed investigation of compliance will only occur if a complaint is made to the medical board.

### **B The Assisted Dying Bill 2013**

The Bill seeks to authorise healthcare professionals to assist the suicide of terminally ill adult patients with capacity who have a clear and settled intention to end their lives (clause 1). It does not provide for reporting, other than by way of death certification, nor does it envisage the creation of a monitoring commission, it thus closely resembles the American Acts. The Bill was introduced in May 2013 as a Private Members Bill by Lord Falconer, the chair of the Commission on Assisted Dying which reported in 2012.<sup>50</sup> Given the nature and constitution of the commission it is perhaps unsurprising that it concluded that:

the current legal status of assisted suicide is inadequate and incoherent... [but that] it is possible to devise a legal framework that would set out strictly defined

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<sup>50</sup> The 'Commission on Assisted Dying' was not an independent inquiry of the ilk of the House of Lords Select Committee established to consider Lord Joffe's Assisted Dying for the Terminally Ill Bill 2004 (*Select Committee on the Assisted Dying for the Terminally Ill Bill, Volume I: Report* HL Paper 86-II (2005)), nor that set up in the aftermath of *Bland* (n.7). Instead this was a commission established with private funding from Terry Pratchett and Bernard Lewis, both supporters of Dignity in Dying with no government remit. The commission's credibility was significantly undermined by the fact that a number of key informants, including the British Medical Association, the Royal College of General Practitioners, declined to give evidence.

circumstances in which terminally ill people might be assisted to die, supported by health and social care professionals, and which would employ robust upfront safeguards to prevent inappropriate requests that did not meet the eligibility criteria from going ahead.

It is suggested that both these conclusions are correct, however it is also argued that this Bill fails to establish such a legal framework, leaving the bulk of the substantive and procedural safeguards to be determined by regulations and/or codes of practice at a later date.

## **1) Qualifying conditions**

### **a. Terminal illness/unbearable suffering**

One of the key differences between the European and American approaches to assisted dying legislation is that the American statutes focus upon terminal illness as a qualifying condition, whilst the European legislation imposes the dual requirement that the patient be suffering unbearably (a subjective assessment) without prospect of improvement (an objective assessment).<sup>51</sup> The Assisted Dying Bill 2013 follows the American model so that there is no requirement that the patient be suffering at all, provided that the patient is terminally ill, clause 1(1), defined as requiring that the patient be diagnosed with an inevitably progressive condition and be ‘reasonably expected to die within six months,’ clause 2(1).<sup>52</sup> This quantitative requirement illustrates the disconnect between the Bill and the (non-US) context within which it is intended to operate. Whilst this qualifying condition is standard within the American Acts, it reflects the fact that section 1861(dd) of the Social Security Act limits Medicare funding for hospice care to the ‘terminally ill’, defined as those with a prognosis of

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<sup>51</sup> See Art. 3 §1 Belgian Act, s.2 (1)(b) Dutch Act. Significantly the Luxemburg Act deviates from the standard model by imposing a requirement that in the case of a contemporaneous request the patient must be terminally ill as well as suffering unbearably without prospect of improvement (Art. 2(3)); this qualification is not applied in the case of an advance request for euthanasia, Art. 4.

<sup>52</sup> Cf. Oregon Death With Dignity Act s.1(12); Washington Death With Dignity Act RCW 70.245.010 (13); cf Vermont Patient Choice at End of Life Act §5281 (10).

six months or less. Such a limitation is inapplicable in the European context, a context of universal healthcare provision. Indeed the requirement of a six-month prognosis is inconsistent with the GMC's broader view of when patients are considered to be 'approaching the end of life,' being 'when they are likely to die within the next twelve months.'<sup>53</sup>

Moreover, this qualification fails to recognise that prognostication is an art, not a science. The legal bright line set out in clause 2(1) simply does not reflect prognostic reality, that prognoses are statistical averages where reliability is at its highest in relation to cancer, but that as the length of life expectancy extends, the reliability of the prognosis declines. Accurate prognosis is even more difficult in the case of degenerative diseases and studies demonstrate that doctors are likely to overestimate how long patients will live, rather than underestimate remaining life expectancy,<sup>54</sup> potentially excluding many people from the ambit of the legislation. Linda Ganzini reported that 25% of Oregon physicians were not confident in their ability to determine the requisite six month life expectancy,<sup>55</sup> a difficulty that is clearly reflected in the Oregon DWDA annual reports. The reports show that the median time from first request to death in Oregon has remained stable at 46-47 days,<sup>56</sup> however, every year patients live longer than six months, the most extreme case occurring in 2008 where a patient survived for 1009 days (more than two and a half years) after making the first request required under the Act.

The limitation of assistance to the terminally ill is likely to prove unworkable, in terms of diagnosing terminal illness with death likely to occur within six months, but it is also incompatible with the motivating factors of compassion, dignity and autonomy, none of

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<sup>53</sup> GMC *Treatment and care towards the end of life: good practice in decision making*, 2010, at para. 2.

<sup>54</sup> W. Hartsell et al, 'Can physicians accurately predict survival time in patients with metastatic cancer? Analysis of RTOG 97-14' (2008) 11(5) *Journal of Palliative Medicine* 723.

<sup>55</sup> L. Ganzini et al "Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act" (2001) 285(18) *JAMA* 2363, at 2368.

<sup>56</sup> *Oregon DWDA Annual Report 2012*, at 6.

which are dependent upon the patient being terminally ill. The language used by the proponents of the Bill, and reflected in the title of the Oregon statute upon which it is based, reflects the fact that the aim of this legislation is to permit the patient to die with dignity. However, it is illogical to argue that the autonomy and dignity of the terminally ill would justify assisted suicide, but exclude those suffering from degenerative diseases such as motor neurone disease, Huntington's and amyotrophic lateral sclerosis ('ALS') – devastating, progressive diseases where the patient will live for much longer than six months, and potentially suffer significantly more than someone who is terminally ill.

It is suggested that the need for effective safeguards does not require access to be restricted to the terminally ill, but that rather assistance should be limited to those suffering unbearably, without prospect of improvement. Such cumulative qualifying conditions form an integral part of the European model of regulation and were included in both Assisted Dying for the Terminally Ill Bills 2004/5. Nevertheless, the Assisted Dying Commission concluded that an unbearable suffering requirement would be too unclear and subjective for doctors to assess,<sup>57</sup> a conclusion that fails to take account of the evidence to the contrary from our European neighbours.

The concept of unbearable suffering is inherently subjective, as Marianne Dees explains 'Unbearable suffering can only be understood in the continuum of the patient's perspectives of the past, the present and expectations of the future.'<sup>58</sup> Indeed it is the subjective nature of the assessment which supports claims to base assisted dying upon the principle of respect for human dignity. Nevertheless, there is an objective element to the assessment because the patient's view that the suffering is unbearable must, in the words of the Dutch Review

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<sup>57</sup> *Commission on Assisted Dying Report* 2012, at 305.

<sup>58</sup> M.K. Dees et al "'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying" (2011) 37 *JME* 727, at 733.

Committees, be palpable to the doctors,<sup>59</sup> whose personal views will affect their assessment of what will constitute unbearable suffering justifying euthanasia, many taking a much narrower view than the legislature and requiring the patient to be terminally ill.<sup>60</sup> As researchers conducting the second evaluation of the efficacy and side-effects of the Dutch Act found in 2012, 85% of Dutch doctors would consider performing euthanasia, but less than 50% would do so in what might be considered the more controversial cases, namely in the case of a psychiatric disorder, dementia or existential suffering.<sup>61</sup>

The concept of suffering is much broader than the experience of pain, encompassing psychosocial and relational distress, and requiring a consideration of the whole person, of how the person perceives her situation.<sup>62</sup> Thus, as the Dutch Supreme Court held in the *Schoonheim* case, it might take the form of degradation of personal dignity and the loss of the opportunity to die with dignity.<sup>63</sup> However, the creation of a robust framework will need to distinguish between forms of suffering, determining which forms will justify a request for assistance without undermining respect for human dignity and life in general. In the *Chabot* case, 1994, the Dutch Supreme Court recognised that psychiatric suffering could constitute unbearable suffering and that the psychiatric nature of the suffering did not preclude a voluntary and well-considered request for termination of life, although it stressed the need for extreme caution in such cases.<sup>64</sup> The Dutch and Belgian Acts both permit euthanasia for physical and mental suffering, although the inclusion of psychiatric suffering has proved to be very

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<sup>59</sup> Regional Euthanasia Review Committees Annual Report 2011, 2012, at 9. Available in English (abridged report) at [http://www.euthanasiecommissie.nl/Images/RTE.JV2011.ENGELS.DEF\\_tcm52-33587.PDF](http://www.euthanasiecommissie.nl/Images/RTE.JV2011.ENGELS.DEF_tcm52-33587.PDF); the full report in Dutch is available at [http://www.euthanasiecommissie.nl/Images/Jaarverslag%20RTE%202011\\_definitief\\_tcm52-33313.pdf](http://www.euthanasiecommissie.nl/Images/Jaarverslag%20RTE%202011_definitief_tcm52-33313.pdf). All references refer to the Dutch version. Hereinafter RERC Annual Report 2011.

<sup>60</sup> M.K. Dees “Perspectives of decision-making in requests for euthanasia: A qualitative research among patients, relatives and treating physicians in the Netherlands” (2013) 27(1) *Palliat Med* 27, at 34.

<sup>61</sup> A. Van der Heide et al *Tweede evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, 2012 [Second Evaluation of the Termination of Life on Request and Assisted Suicide Act], available at [www.zonmw.nl/publicaties](http://www.zonmw.nl/publicaties), at 13.

<sup>62</sup> For an excellent consideration of the nature of suffering see Eric Cassel *The Nature of Suffering and the Goals of Medicine*, New York: OUP, 2003.

<sup>63</sup> *Schoonheim* case, *Nederlandse Jurisprudentie* 1985, no. 106 (Hoge Raad).

<sup>64</sup> *Chabot* case, *Nederlandse Jurisprudentie* 1994, no. 656 (Supreme Court), at 3155.

controversial, not least with psychiatrists, and the statistics show that very few such cases result in either euthanasia or PAS every year. For example, in the Netherlands in 2011 there were 13 notifications involving patients with psychiatric problems, representing 0.35% of all notifications.<sup>65</sup> It is suggested that psychiatric suffering should not be excluded from the remit of the legislation, but that it should be subject to a mandatory second opinion by a psychiatrist.

Equally controversial is what has been termed ‘existential suffering’, that is where the patient is tired of life. The Belgian legislation excludes such suffering by requiring that the hopeless medical condition and unbearable, unrelievable pain result from a serious and incurable accidental or pathological condition, §1. In the Netherlands the question of whether existential suffering could constitute unbearable suffering, formed the focus of the Supreme Court’s consideration in the case of *Brongersma*,<sup>66</sup> where the court held that unbearable suffering must have a somatic origin, that is it must be caused by either a diagnosable physical or psychiatric illness. Whilst this clarification is to be welcomed, it is unlikely to put an end to the debate, not least because in cases where the patient is ‘tired of life’ she (like Senator Brongersma) is likely to have a number of physical ailments and focus on the suffering caused thereby may well be sufficient to constitute palpable unbearable suffering.

The Dijkhuis committee set up by the KNMG (the Royal Dutch Medical Association) to consider the matter in the wake of the Supreme Court’s ruling, rejected the narrow view that the doctor’s domain is limited to somatic suffering<sup>67</sup> a position accepted by the KNMG on the basis that existential suffering falls within the medical domain because non-somatic dimensions of suffering may also ‘require alleviation or remediation through palliative

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<sup>65</sup> RERC *Annual Report 2011*.

<sup>66</sup> HR 00797/02, 24/12/2002; (2003) 326 *BMJ* 71.

<sup>67</sup> *Op zoek naar normen voor het handelen van artsen bij vragen om hulp bij levensbeëindiging in geval van lijden aan het leven*, (*The search for standards for doctor’s intervention in cases of euthanasia requests for existential suffering*), Utrecht: KNMG, 2004, at 39 - 43.

care.’<sup>68</sup> Thus the second evaluation of the Act (2012) recognised a shift in attitude, so that whilst the predominant source of the suffering should be medical in nature, account may also be taken of existential suffering.<sup>69</sup> There is clearly some scope for flexibility concerning what will constitute unbearable suffering without somatic suffering and it is suggested that the clarity of the Belgian approach is preferable, namely that legislation should specify that suffering be due to a serious and incurable accidental or pathological condition. Subject to that proviso, it is suggested that the concept of unbearable suffering is not overly broad as it is tempered by the fact that the doctor must consider it palpable.

In addition to the requirement that the patient be suffering unbearably, both the Dutch and Belgian Acts require that suffering to be unrelievable, an objective assessment and thus dependent upon medical opinion. As the Dutch Supreme Court made clear in the *Chabot* case, if a patient rejects a realistic alternative to termination of life that could alleviate her suffering, the doctor will be unable to conclude that the suffering is unbearable and without any prospect of improvement.<sup>70</sup> What constitutes a realistic alternative will be a subjective assessment and the extent to which the patient will be required to accept treatment will depend upon the burdens such treatment will impose upon the patient and the need for a proportional benefit.<sup>71</sup> However, it is becoming apparent that palliative sedation may be regarded as a realistic alternative to termination of life in alleviating the patient’s suffering. This is extremely problematic, as Margaret Battin has argued, palliative sedation: ‘may end pain, but it also ends life. It does so in two ways: it immediately ends sentient life and the possibility for social interaction, and then, because artificial nutrition and hydration are

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<sup>68</sup> KNMG 2011 position statement, at 21.

<sup>69</sup> See A. Van der Heide et al Second Evaluation n.61, at 12.

<sup>70</sup> *Chabot* case n.64, at 3155.

<sup>71</sup> See for example Federale Controle- en Evaluatie Commissie Euthanasie *Vijfde Verslag Aan de Wetgevende Kamers (2010 - 2011)* [Fifth Report], 2012, at 14. Available at <http://www.health.belgium.be/internet2Prd/groups/public/@public/@dg1/@acutecare/documents/ie2divers/19078961.pdf>.

usually withheld, it also ends biological life.’<sup>72</sup> This is incompatible with one of the primary motivations given for requesting assisted dying, namely to retain control and choose a death that reflects the way we have lived our lives. The sedated patient’s suffering may be relieved, but this comes at a high cost, the patient is rendered unconscious, reduced to being an object of concern, devoid of those attributes which define a person. Absent an expressed desire for palliative sedation by the patient, it is suggested that this process is inconsistent with respect for both autonomy and dignity and therefore that palliative sedation should not be regarded as an alternative to assisted dying that could render the patient’s suffering relievable.<sup>73</sup>

The Assisted Dying Bill 2013 should be amended to permit assistance in cases where the patient is suffering unbearably without prospect of improvement, by its very nature the subjectivity of the unbearable suffering requirement complements the promotion of dignity, without increasing the scope for abuse. Moreover, it is suggested that rather than restricting access to assisted dying by imposing a requirement that the patient be terminally ill, a much more effective, and arguably justifiable, restriction would be to accept that whilst unbearable suffering can justify assisted dying, it should be subjected to additional safeguards where death is not imminent. This is the approach adopted by the Belgian Act which imposes a mandatory cooling-off period and an additional, more rigorous consultation requirement in such cases. In practice the degree to which life is shortened in each jurisdiction is small, but some people do elect for termination of life when they are not expected to die in the short term, for example in Belgium 9% of euthanasia cases concern patients who were not expected to die in the near future, largely patients suffering from progressive neurological disorders, including Alzheimer’s, Huntington’s and ALS.<sup>74</sup> The Bill’s restrictive use of ‘terminal illness’ as a qualifying condition is nothing more than an artificial restriction upon

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<sup>72</sup> M. Battin “Terminal Sedation: Pulling the Sheet over Our Eyes” (2008) 38(5) *Hastings Center Report* 27, at 27-8.

<sup>73</sup> See also RERC *Annual Report 2011*, at 16, concluding that if the patient refuses palliative sedation it will not be considered a reasonable alternative to euthanasia.

<sup>74</sup> FCCE *Fifth Report*, n.71, at 8.



assisted dying which does not reflect any principled stand point. It is merely a device intended to make the Bill appear more restrictive and thus more palatable, however, the illusion of control does not equate with true control. A more principled approach demands that access be provided to those suffering unbearably without prospect of improvement with robust safeguards to ensure assisted dying remains a last resort.

**b. The patient must be an adult with capacity, clause 1(2)(c)<sup>75</sup>**

Both the attending and consulting doctors must be satisfied that the patient has the requisite capacity to make the decision to end her own life (clause 3(3)(b)). Capacity is decision-specific, that is the greater the import of the decision, the higher the degree of capacity that will be required.<sup>76</sup> In the case of assisted dying it can be expected that an extremely high degree of capacity will be required and in case of doubt the principle of *in dubio pro vitae* will apply. Every adult is presumed to have capacity (s.1(2) Mental Capacity Act 2005), however, the Assisted Dying Commission argued that it is necessary to invert the presumption in the case of assisted dying due to the serious nature of the decision.<sup>77</sup> It is certainly true that requesting assistance in dying is a serious matter, however a refusal of treatment, even life-sustaining treatment, will of itself not trigger a capacity assessment and it is difficult to see why a request for assisted dying should displace the presumption. The Bill fails to specify how capacity will be assessed or make provision for a psychiatric filter,

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<sup>75</sup> Like the American Acts, the Assisted Dying Bill 2013 restricts access to assistance in dying to adults. By contrast, both the Dutch and the Belgian Acts envisage the possibility of minors requesting assistance in dying, although such assistance is rare. The Dutch Act applies the standard law relating to medical treatment (Art. 450 (2) Law on Contracts for Medical Treatment (WGBO)) to the euthanasia context, allowing children aged 12 and over to request euthanasia with parental consent, or minors of 16 and over to make the decision themselves, albeit with parental involvement (s.2(3)(4).) The Belgian law is much narrower; only emancipated minors may currently make a valid request (Art. 3§1), although the Belgian Parliament is currently considering an amendment to bring the Act into line with the Law on Patients' Rights which recognises the right of a minor capable of a reasonable appreciation of their situation to consent or refuse treatment, Article 12(2). Unfortunately the issues involved in permitting minors to request assisted dying are too many and too complex to explore in greater depth in this article due to considerations of length.

<sup>76</sup> *In re T* n.11, per Lord Donaldson MR at 113; *B n. 12*, per Dame Elizabeth Butler-Sloss P, at para. 31; *Bland* n. 6, per Lord Goff at 864.

<sup>77</sup> Commission on Assisted Dying Report 2012, at 308.

leaving such matters as ‘assessing whether the person has capacity to make such a decision [and] recognising and taking account of the effects of depression or other psychological disorders that may impair a person’s decision-making...’ to be set out in a code of practice.<sup>78</sup>

It is suggested that given the serious nature of these matters, and the need for a rigorous framework, any such provisions should be part of the parent Act. A request for assistance should not act as an automatic trigger for a formal capacity assessment, such an assessment only being appropriate where there is disagreement between the consulting and attending doctors as to the patient’s capacity. Moreover, a psychiatric referral is not required to assess capacity, but should be mandatory only where a psychological disorder is considered to be potentially impairing a person’s decision-making.

### **i) Depression**

There is conflicting evidence about the correlation between depression and a request for assisted dying,<sup>79</sup> although reactive depression is a common response to life-limiting disease. Whilst depression will not necessarily render the individual unable to make a valid request, it does raise questions about the individual’s capacity that need to be addressed. For that reason the Dutch Regional Review Committees (RRCs) have advised that where the attending doctor considers that depression may be affecting the patient’s decisional capacity she should seek the advice of a psychiatrist in addition to the statutory consultation requirement<sup>80</sup> and the Oregon Act provides for a mandatory ‘counselling referral’ to a psychiatrist or psychologist in such cases, s.3.

Requests for assistance are likely to be made in circumstances where the patient’s symptoms overlap with indicators of depression including fatigue, insomnia, weightloss and feelings of

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<sup>78</sup> Cl. 8(1)(a) Assisted Dying Bill 2013.

<sup>79</sup> I. Levene, M. Parker “Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review” (2011) 37 *JME* 205.

<sup>80</sup> RERC *Annual Report 2011*, at 11.

hopelessness. However, care should be taken to avoid the psychiatrisation of assisted dying and a psychiatric consultation should not be sought merely to validate the attending doctor's view that the patient has the capacity to make a valid request. Linda Ganzini found that more than three quarters of those requesting PAS in Oregon were not depressed and recommended the use of a screening tool such as the Hospital Anxiety and Depression Scale (HADS) to identify patients who might be suffering from depression and refer those patients on for psychiatric evaluation.<sup>81</sup> This approach seems eminently sensible, recognising that a psychiatric evaluation will not be necessary in every case and therefore should not become an undue burden upon the patient's ability to access assisted dying, or further stigmatise the process of requesting assistance.

## **ii) Anticipatory requests for assistance in dying**

In common with the American Acts, the Bill makes no provision for the exercise of precedent autonomy, unlike the Dutch, Belgian and Luxemburg Acts which provide that a patient can execute an advance euthanasia directive, requesting that her life be terminated in specified circumstances if she lacks capacity.<sup>82</sup> Clearly such a request would differ from the advance decisions given effect under the Mental Capacity Act, which limits such decisions to the refusal of treatment, but in principle, there is no reason why a specific advance euthanasia request, applicable in the circumstances, could not represent a valid request. However, the difficulties associated with determining the conditions in which such requests should operate are well demonstrated by the experience of the Benelux countries. The Belgian and Luxemburg Acts restrict advance requests to cases where a serious and incurable accidental

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<sup>81</sup> L. Ganzini et al "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey" (2008) 337 *BMJ* 1682. For similar findings in relation to the Netherlands see M. Van der Lee "Depression, Euthanasia, and Assisted Suicide", chapter 18, in S.J. Youngner & G.K.Kimsma (eds) *Physician-Assisted Death in Perspective Assessing the Dutch Experience* Cambridge: CUP, 2012.

<sup>82</sup> S.2(2) Dutch Act, Art. 4 Belgian Act, Art. 4 Luxemburg Act.

or pathological condition has rendered the patient irreversibly unconscious,<sup>83</sup> a state where the patient would not usually be considered to be suffering.<sup>84</sup> By contrast, the Dutch Act subjects anticipatory requests to the same requirements as contemporaneous requests, the most problematic of which in this context is the requirement that the patient be suffering unbearably. Thus, the Dutch Act has generally been considered to permit euthanasia in cases of dementia, for example, but to exclude cases of coma unless the patient is in a state of semi-consciousness and visibly distressed.<sup>85</sup>

Thus there is no consistency in this area, the Belgian approach restricts the operation of precedent autonomy to the unconscious patient, the Dutch to those who have sufficient consciousness to experience unbearable suffering. As Buchanan and Brock note, the fact that an individual's interests may be radically and unforeseeably different from those anticipated significantly weakens the argument for precedent autonomy.<sup>86</sup> Nevertheless, a principled approach to protecting both internal and external understandings of dignity is required. Thus, if it is accepted that the internal conception of dignity requires that limits be placed upon the eligibility to request assistance in dying, those limits should also be applied to the anticipatory decision-making context, requiring, as in the Netherlands, that the patient can be said to be suffering unbearably. Whilst it accepted that this approach will exclude patients in a persistent vegetative state or coma, it is suggested that this is consistent with the demands of universal dignity and that personal dignity can in such cases be protected by recognising the validity of applicable advance refusals of life-sustaining treatment, including ANH.

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<sup>83</sup> Art. 4 §1; Art. 4(1) Luxemburg Act.

<sup>84</sup> *NHS Trust A v M; NHS Trust B v H* [2001] Fam. 348, *per* Dame Butler-Sloss, at 363.

<sup>85</sup> RERC *Annual Report 2011*, at 15-16. This is also the view taken by the KNMG in its 2010 guidance relating to euthanasia in cases of reduced consciousness which adopts the Glasgow-coma score, recommending that a patient scoring below 6 is in a deep coma and therefore cannot be considered to be suffering, KNMG *Richtlijn euthanasie bij een verlaagd bewustzijn*, Utrecht, 2010.

<sup>86</sup> A. Buchanan & D. Brock *Deciding for others: the ethics of surrogate decisionmaking*, CUP, 1990, at 105-6.

Anticipatory requests are likely to be of most value, and least controversial in cases of degenerative diseases such as motor neurone diseases, where the patient retains consciousness, but is progressively debilitated by the condition, losing all ability to communicate. In such cases a clearly applicable anticipatory request for euthanasia,<sup>87</sup> setting out the point at which assistance should be triggered, should be respected. For example in *Re AK (medical treatment: consent)*<sup>88</sup> a motor neurone disease sufferer was able to create a valid and applicable directive requiring that ventilation be discontinued two weeks after he ceased being able to communicate; it is suggested that a request for euthanasia formulated upon the same terms should be equally valid. The implementation of an anticipatory request is likely to be most controversial in the case of dementia where the scope for suffering is immense, but where there is considerable potential for doubts concerning revocation and arguments that the now severely demented patient (P2) is a very different person to the person she was at the time of formulating the advance request (P1) due to the loss of psychological continuity.<sup>89</sup> Dresser argues that the patient should be treated in accordance with her best interests rather than being subjected to the paternalistic views held by her former self.<sup>90</sup> However, an assessment of the patient's best interests prioritises the patient's current physical interests rather than recognising her as a person with interests and values that transcend dementia. As argued above, dignity requires that individuals be able to make choices reflecting their innermost beliefs and values about the circumstances in which they

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<sup>87</sup> PAS is unlikely to be a viable option in such cases. Despite the fact that Diane Pretty suggested that she required assistance in committing suicide, it is difficult to conceive of a manner in which she could be so assisted given the extent to which the disease had progressed, rendering her unable to swallow or operate a syringe driver.

<sup>88</sup> [2001] 1 FLR 129

<sup>89</sup> D. Parfit *Reasons and Persons*, OUP, 1986. For a detailed consideration of this issue see R.S. Dresser 'Missing persons: legal perceptions of incompetent patients' (1994) 46 *RULR* 609; R.S. Dresser 'Advance Directives, self-determination, and personal identity' in C. Hackler et al (eds) *Advance Directives in Medicine*, Greenwood Press, 1989; N. Cantor, 'Discarding Substituted Judgment And Best Interests: Toward A Constructive Preference Standard For Dying, 'Previously Competent Patients Without Advance Instructions' (1996) 48 *RULR* 1193, at 1210; R. Dworkin n.31; N. Rhoden 'Litigating life and death' (1988) 102 *Harv LR* 275; A. Maclean 'Advance directives, future selves and decisionmaking' (2006) 14 *Med LR* 291.

<sup>90</sup> N.89.

would wish to be treated, these must be the determinative interests that survive incapacity, trumping current experiential interests. Engaging in bifurcation of the individual is inconsistent with promoting dignity in either guise, rather it is submitted that a unitary approach must be taken, that it must be accepted that all lives go through differing phases and that each phase, including a demented phase, is simply part of the same life. That being so, the principle of dignity requires that an individual's competent choices made with capacity must be respected, and that additional safeguards be put in place to ensure the protection of the universal dignity of human life, reflecting the additional need for protection in the case of dementia. Therefore, it is suggested that the advice of the Dutch RRCs be adopted, that in dementia cases an independent psychiatrist or geriatrician should be consulted in addition to the usual consultation requirement, ensuring that the due care criteria have been met.<sup>91</sup>

## **2) The absolute requirement of a voluntary informed request for assisted dying**

The primary safeguard in any legislation that legalises AVE and PAS must be to ensure that the termination of life only takes place at the request of the patient and that that request is not a coerced choice masquerading as free will. Thus the Bill, along with each of the jurisdictions under consideration require both the attending and consulting doctor to assure herself that the patient's request is voluntary, fully informed, well considered and enduring. It is vital that these elements are verifiable and so detailed records of the request, information provided and of discussions of alternatives to assisted dying should be kept and should feed into the monitoring process.

### **a. Physician assisted suicide as an indicator of voluntariness**

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<sup>91</sup> RERC *Annual Report 2011*, at 12.

In line with the recommendation of the Assisted Dying Commission,<sup>92</sup> the Bill would only permit PAS, placing it firmly within the American model of regulation. The doctor plays an active and necessarily causal role in the patient's death in both AVE and PAS,<sup>93</sup> but PAS is generally regarded as less controversial than euthanasia, particularly because it emphasises the patient's individual responsibility and increases the patient's control of her death.<sup>94</sup> However, the relevance of this distinction is probably overstated, as the Dutch Health Council has recognised, 'The context in which the treatment takes place seems far more important than the form assumed by the assistance in a specific case.'<sup>95</sup>

The House of Lords Select Committee approved of the preference for PAS set out in the ADTI 2004 for the above reasons, but failed to address the evidence of a number of studies that have shown that efficacy problems are quite frequently encountered with PAS<sup>96</sup> and that it may not lead to the 'gentle and easy' death desired. For example in 2012 one Oregonian recovered consciousness two days after ingesting the drugs, remaining minimally responsive until he died six days later of the underlying condition.<sup>97</sup> Such problems undoubtedly explain the fact that despite the KNMG's expressed preference for PAS, over 90% of Dutch assisted deaths are the result of euthanasia.<sup>98</sup> Thus where permissible assistance is restricted to PAS, the doctor is placed in the unenviable position of assisting someone to commit suicide by

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<sup>92</sup> Report of the Assisted Dying Commission, at 318.

<sup>93</sup> D.W. Brock *Life & Death* (1993) Cambridge: CUP, at 55.

<sup>94</sup> See for example KNMG *Vision on Euthanasia*, Utrecht, 1995.

<sup>95</sup> Dutch Health Council Euthanasie. *Advise inzake euthanasie uitgebracht door de Gezondheidsraad aan de Minister en de Staatssecretarie van Volksgezondheid en Milieuhygiëne [Euthanasia: Advice concerning Euthanasia from the Health Council to the Minister and the Secretary of State for Public and Environmental Health]* Den Haag, Staatsuitgeverij 1982, at 15.

<sup>96</sup> See for example JH Groenewoud et al "Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands." (2000) 342 *N Engl J Med* 551. – arguing that 16% of PAS in the Netherlands led to serious complications or did not work. Complications ranged from technical problems e.g. insertion of IV to nausea / vomiting problems and problems with completion, e.g. the patient woke up. Similarly, in 2012, the Belgian FCCE reported that of the 12 cases of assisted suicide (less than 1% of the assisted dying cases for the period) eight patients died without further intervention, but that the doctor intervened to give a muscle relaxant in the remaining four cases, suggesting a failure rate of one in three in assisted suicide cases, FCCE *Fifth Report*, n.71, at 17.

<sup>97</sup> Oregon DWDA Annual Report 2012, at 2.

<sup>98</sup> In 2010 only 0.1% of all deaths in the Netherlands were the result of PAS, 2.8% resulted from AVE.

providing access to the lethal drugs, but prevented from intervening to ensure the patient dies quickly and without further suffering when complications arise. Such cases will be distressing for all concerned and there appears to be no principled reason for prohibiting doctors from intervening in such cases.

Moreover, it may be very difficult to accurately draw the line between euthanasia and PAS. Whilst the American model can be characterised as a licensing scheme whereby doctors are permitted to prescribe lethal drugs to qualifying patients, the Assisted Dying Bill 2013 appears to envisage a much greater degree of participation by the assisting healthcare professional. Thus assistance may be rendered in three ways, the assisting healthcare professional may 'prepare [the] medicine for self-administration ..., prepare a medical device which will enable [the] person to self-administer the medicine; and assist that person to ingest or otherwise self-administer the medicine,' but 'the decision to self-administer the medicine and the final act of doing so must be taken by the person for whom the medicine has been prescribed,' clause 4(4). Thus, the healthcare professional may mix the medicine and may set up a device such as a syringe driver, but it is not entirely clear what the third option is intended to cover - might it perhaps just mean holding a glass so that the individual can drink through a straw? Or might it mean pouring the mixture into the person's mouth, leaving her to swallow it? At what point will the doctor have crossed the Rubicon into the realm of AVE? The dividing line between PAS and AVE is very difficult to draw, but the third method appears to be nothing more than a catch-all clause, designed to permit whatever assistance is required. Such poorly formulated clauses, without additional information in the explanatory notes, do not inspire much confidence in the Bill's ability to set effective safeguards upon the assisting dying and require urgent clarification.

Arguably the fact that the Assisted Dying Bill 2013 is restricted to assisted suicide is a pragmatic decision designed to make the Bill more likely to be passed. Certainly the



American experience in the lead up to the enactment of the Oregon Act suggests that restricting legislation to PAS and referring to ‘death with dignity’ rather than assisted suicide makes the Bill much more palatable to voters.<sup>99</sup> Similarly, it could be suggested that reference to ‘assisted dying,’ rather than PAS, might make the Bill more acceptable to doctors, framing the doctor’s role as helping to bring the dying phase to an end, rather than ending life. In a systematic review of the literature Ruaidhri McCormack found that the majority of UK doctors do not support either AVE or PAS,<sup>100</sup> whilst Clive Seale found that although 34% of doctors supported AVE if the patient were in pain and terminally ill, that figure rose to 35.2% supporting PAS in the same circumstances,<sup>101</sup> suggesting that by limiting the role of the physician to that of prescriber, the Bill will be slightly more palatable to the medical profession. Nevertheless it is clear that the degree of support that was so instrumental in forming the euthanasia policy in the Netherlands is lacking within the British medical profession.<sup>102</sup> PAS enables the doctor’s involvement to be viewed as a partnership with the patient rather than as being the agent of death and it affirms the voluntariness of the patient’s request, but whilst it would be legitimate for the Bill to prefer PAS, it is suggested that limiting assistance to PAS in all cases is discriminatory (excluding those who are physically unable to ingest the medication), is liable to leave the patient in a much worse position if problems occur, and lacks a principled basis.

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<sup>99</sup> R.P. Jones *Liberalism’s Troubled Search for Equality: Religion and Cultural Bias in the Oregon Physician-Assisted Suicide Debates*, Notre Dame: University of Notre Dame Press, 2007, citing D. Humphrey and M. Clement *Freedom to Die: People, Politics, and the Right-to-Die Movement*, New York: St Martin’s Griffin, 2000 at 246.

<sup>100</sup> R. McCormack et al “Attitudes of UK doctors towards euthanasia and physician-assisted suicide: A systematic literature review” (2012) 26(1) *Palliat Med* 23.

<sup>101</sup> C. Seale “Legalisation of euthanasia or physician-assisted suicide: survey of doctors’ attitudes” (2009) 23 *Palliat Med* 205.

<sup>102</sup> See findings reported by C. Seale n.101, R. McCormack n.100, W. Lee et al “Survey of doctors’ opinions of the legalisation of physician assisted suicide” (2009) 10(2) *BMC Medical Ethics* doi:10.1186/1472-6939-10-2.

**b) The role of the doctor in ensuring the request is voluntary, fully informed, well-considered and enduring.**<sup>103</sup>

Each of the jurisdictions requires the attending doctor to be satisfied that the patient's request is voluntary, fully informed, well-considered and enduring. However, the procedural safeguards designed to ensure this was the case vary due to the way in which compliance is monitored in the European model and largely assumed in the American model of regulation. Generally the European regulatory schemes rely upon the doctor developing a dialogue with her patient, and documenting that dialogue detailing the quality and nature of the request to demonstrate compliance with the due care criteria. The reports are scrutinised by monitoring committees, to ensure that doctors were diligent in satisfying themselves that the patient's request meets the criteria and in complying with all the other due care criteria. By contrast the American model of regulation requires detailed records to be kept, noting the date of the first and second request for example, but then has what can only be described as a very light-touch monitoring mechanism which assumes, rather than monitors compliance.

The Assisted Dying Bill 2013 again follows the American model by requiring a witnessed written request (regrettably no provision is made for anyone unable to complete a written request),<sup>104</sup> followed by a cooling off period of 14 days,<sup>105</sup> reduced to 6 days if the attending and consulting doctors believe the patient will die within one month.<sup>106</sup> Prior to the assistance being given the patient must confirm that she has not revoked her declaration, effectively restating it. The Bill requires the patient's request to be made on an 'informed

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<sup>103</sup> These elements have proved unproblematic in each jurisdiction and thus are only briefly considered due to space constraints. For a more detailed consideration of each element see S. Halliday "Regulating AVE: what can England & Wales learn from Belgium and the Netherlands?" in Garwood-Gowers et al (eds) *Contemporary Issues in Health Law and Ethics*, Elsevier Science Ltd, 2005, chapter 14; and J. Griffiths et al *Euthanasia and Law in Europe*, Oxford: Hart, 2008

<sup>104</sup> Cl. 3 (1)(a) Assisted Dying Bill 2013.

<sup>105</sup> Cl. 4(2)(d) Assisted Dying Bill 2013.

<sup>106</sup> Cl. 4(3) Assisted Dying Bill 2013.

basis,<sup>107</sup> but leaves the question of what information is required to be determined by the Secretary of State in a code of practice.<sup>108</sup> Such an approach is inconsistent with the desire to establish ‘robust upfront safeguards’, particularly as the Bill appears to envisage an American style light-touch monitoring of compliance, discussed below.

### **c) The role of palliative and social care filters**

Each of the jurisdictions requires the patient’s request to be informed, indeed without such information the patient will be in no position to make the requisite well-considered request. At a very minimum both the attending and consulting doctors should ensure that the patient has a clear understanding of her diagnosis and prognosis and what the assistance will entail, but this is left implicit in the Assisted Dying Bill 2013. However the Bill does stress the need for the two doctors to ‘be satisfied that the [patient] ... has been fully informed of the palliative, hospice and other care which is available’ to her. This provision does not require the patient to accept palliative care, nor does it guarantee her all the palliative care that might benefit her, but it does require a discussion of the care available to her.

This is not a palliative care filter, the requirement could conceivably be met via an information leaflet, but if the required information is to serve any real purpose it needs to be provided by a specialist in palliative care (either a doctor or nurse) as part of an ongoing dialogue about choices and care available to the individual at the end-of-life, rather than being regarded as a checkbox on the route to assisted dying. None of the Acts imposes a palliative care filter, although as Guenter Lewy argues, in the majority of cases in Belgium there is a *de facto* palliative care filter because a requirement that a palliative care consultation take place is part of the guidelines for clinical practice adopted by the majority of institutions within Caritas Flanders, an organisation representing about 65% of hospitals

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<sup>107</sup> Cl. 3 Assisted Dying Bill 2013.

<sup>108</sup> Cl. 9 Assisted Dying Bill 2013.

and 40% of nursing homes in Flanders.<sup>109</sup> Moreover, evidence from each of the jurisdictions suggests that since assisted dying was legalised (although not necessarily because of that fact), doctors have become more knowledgeable about palliative care and of the part it plays in taking a more holistic approach to caring for the dying.<sup>110</sup> Indeed, evidence from both European and America shows that strengths in palliative care can co-exist with assisted dying, that they should be regarded as complementary to one another, rather than as alternatives.<sup>111</sup>

Throughout this article I have argued that dignity demands that individuals are permitted to make their own choices about how they die, including being able to request assistance. However, choice is meaningless if the individual is requesting assistance because she is not informed of, or cannot access palliative or social care, that would raise her quality of life to that which she would consider acceptable. Although the UK is renowned for its contribution to the palliative care field, provision is patchy and so access can be difficult in some areas, it also still very much tailored towards the cancer patient. Progress is being made on both these fronts as part of the Government's end-of-life strategy, but further investment will be needed to ensure that demand can be met. Similarly, the discussion of existential suffering illustrates the need for a multi-agency approach to requests for assistance in dying, particularly in cases where the patient is not expected to die within the short term. Thus a social care filter is also required, whereby social workers should be involved to consider whether any services could

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<sup>109</sup> G.Lewy *Assisted Death in Europe and America: Four Regimes and Their Lessons*, Oxford: OUP, 2010, at 83. See also T. Smets et al "Legal Euthanasia in Belgium Characteristics of All Reported Euthanasia Cases" (2010) 48(2) *Medical Care* 187, at 192; J. Lemiengre et al. „Ethics policies on euthanasia in hospitals—a survey in Flanders (Belgium)" (2007) 84 *Health Policy* 170.

<sup>110</sup> See A. Van der Heide et al Second Evaluation n.61, at 13, E.R.Goy et al "Oregon hospice nurses and social workers' assessment of physician progress in palliative care over the past 5 years" (2003) 1 *Palliat Support Care* 215, L. Gazini et al, "Oregon physician's attitudes about and experiences with end-of-life care since passage of the Oregon Death With Dignity Act" (2001) 285 (18) *JAMA* 2363, J. Bernheim et al, "The Belgian model on comprehensive end-of-life care: palliative care and legal euthanasia as complementing, non-antagonistic developments I. Historical, epidemiological and regulatory evidence" (2012) 68(11) *Tijdschrift voor Geneeskunde* 539, J. Bernheim et al, "The Belgian model on comprehensive end-of-life care: palliative care and legal euthanasia as complementing, non-antagonistic developments II. Domestic and international controversies" (2012) 68(11) *Tijdschrift voor Geneeskunde* 549.

<sup>111</sup> *Ibid.*

be provided to relieve the patient's suffering, improving her quality of life. It is suggested that were any form of assisted dying to be introduced, the Act should be accompanied by a palliative care Act as in Belgium and Luxemburg and the necessary investment, guaranteeing patients access to palliative care. Moreover, a similar investment will need to be made in the social care field, a field that has much to offer in the context of empowering individuals and improving their quality of life.

### **3. The independent consultation requirement**

Each of the jurisdictions incorporates a form of peer-review via a consultation requirement. This is an extremely important quality assurance mechanism, requiring the consultant to confirm the attending doctor's medical opinion and that the patient's request satisfies the validity criteria. This requirement provides the only form of external review that takes place prior to the assistance in dying and a measure of importance of this requirement can be seen in the stringency with which the Dutch review committees have applied this requirement, with failure to comply with the requirement being one of the most common reasons for a finding that the doctor has not acted with due care and the case being referred to the prosecutorial authorities and/or the medical inspectorate.

If the consultation requirement is to be an effective safeguard and more than a mere rubber stamping exercise the consultant must be truly independent, independent of both the attending doctor and the patient. However, in the Assisted Dying Bill 2013 independence is only defined in relation to the attending doctor, not the patient, clause 3(1)(b)(ii). This is clearly a shortcoming and rather surprising given that the Assisted Dying Commission did

recognise the need for the consulting doctor to have no pre-existing professional relationship with the patient.<sup>112</sup>

Some guidance concerning how independence might be ensured can be gained from the way in which the requirement has been interpreted by the Dutch and Belgian monitoring commissions. They have stressed that the doctor must not belong to the same practice as the attending doctor, must not have an ongoing professional relationship with her and must not be related, or have a friendship with her; regular cooperation with the same consultant is likely to raise questions about the independence of that consultant.<sup>113</sup> With regards to the patient the committees have confirmed that the consultant must not have treated the patient in the past, or currently be responsible for the patient's care, she must also not be related to the patient or a personal friend.

If the peer review is to operate effectively the consulting doctor must be at least competent as to the pathology concerned, but it would clearly be a more effective safeguard if the consultant were required to be a specialist in the given area. Of all the jurisdictions under consideration, such a requirement is only found in the Belgian Act, and then only in the case of a patient who is not expected to die within the short term. The Belgian Act adopts a dual consultation requirement in such cases, requiring that the second consultant be either a specialist in the patient's pathology, or a psychiatrist, Article 3 §3(1). Additional lessons can be learnt from the context in which assisted dying operated in the Netherlands and Belgium. In both jurisdictions a network of euthanasia consultants has been created, the SCEN network in the Netherlands and the LEIF network in Flanders.<sup>114</sup> Members of these networks are specially trained to provide euthanasia consultations. The Dutch Review Committees have

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<sup>112</sup> Assisted Dying Commission Report, 2012, at 313.

<sup>113</sup> RERC *Annual Report 2011*, at 20.

<sup>114</sup> Within Wallonia the EOL network is being developed to fulfil the same function for the French-speaking part of Belgium.

consistently recommended the use of a SCEN consultant, emphasising the high quality of the consultation provided and the view taken by the KNMG is that only SCEN consultants should be used. The professionalisation of the consultation process has much to recommend it – it should ensure a high quality consultation, functioning not only as a means of confirming the factors above, but also operating as a form of *a priori* review. The professionalisation of the consultation process has much to recommend it – it should ensure the availability of highly trained, experienced consultants throughout the country, experts who are able to offer advice, having a thorough knowledge of the statutory requirements and who can also offer support to the attending doctor. It is suggested that provision for a similar specialist panel should be established under the auspices of the Assisted Dying Bill 2013, with provision for state funding. It could work in a similar manner to the second opinion appointed doctors scheme administered by the Care Quality Commission to provide second opinions under the Mental Health Act 1983, and the panel of Independent Assessors trained and accredited by the Human Tissue Authority to assess potential donations of some living organ transplants under the Human Tissue Act. Moreover, it is suggested that the practice of ‘assisted dying’ consultation be restricted to NHS practitioners, to avoid the possibility of private practice developing to provide second opinions.<sup>115</sup>

In addition to consulting another doctor, it is suggested that the Bill should be amended to incorporate a duty to consult other members of the healthcare team and together with a recommendation to consult the patient’s family, as required in Belgium and recommended in the Netherlands.<sup>116</sup> In the case of other members of the healthcare team, often nurses and social workers have no voice in discussions about assisted dying, although both, particularly nurses in a residential or hospital setting, are likely to know the patient very well and may well be able to elucidate the motivations for the patient’s request, enabling a better

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<sup>115</sup> Cf. cl. 1 ADTI Bill 2004.

<sup>116</sup> Art. 3 §2 Belgian Act, KNMG *The role of the physician in the voluntary termination of life*, Utrecht, 2011.

assessment of its voluntariness and durability. Similarly, in the case of family members, provided that the patient consents to their involvement, it is likely that they will be able to give further information relevant to assessing the patient's request and to provide valuable support to the patient.

#### **4. The Reporting requirement**

The reporting requirement is a central feature of the European model of regulation – it is a key requirement that justifies the doctor's actions and failure to report will render the doctor liable to prosecution. The report forms the basis of the procedural review that follows assistance in dying in each of the European jurisdictions. However, whilst the Assisted Dying Commission envisaged reporting via a death certificate and to a national monitoring commission,<sup>117</sup> the Bill only requires reporting via a death certificate and makes no provision for a monitoring commission. Thus the Bill requires even less accountability than the Oregon legislation which provides for both the attending doctor and the dispensing pharmacist reporting to the Oregon Department of Health Services, s.3.11. It will be recalled that the Commission on Assisted Dying concluded that robust upfront safeguards would prevent inappropriate requests from going ahead, however, it is suggested that there is little point in creating robust upfront safeguards if no accountability mechanisms are to be established to ensure those safeguards are not being circumvented. Thus, the key failing of the Assisted Dying Bill 2013 may be seen to be its failure to establish a robust reporting procedure, enabling compliance monitoring by an independent commission.

#### **5. The need for a commission to monitor compliance and evaluate the law**

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<sup>117</sup> Assisted Dying Commission Report, 2012, at 319.



The Assisted Dying Bill 2013, like its American counterparts, makes no provision for a monitoring commission to review compliance with the Act. For example, the Oregon Act does not require an investigation of every case reported to the monitoring authority, the Oregon Department of Health Services, merely requiring the ODHS to review a sample of records pursuant to the Act and the maintenance of detailed records by the attending doctor, s.3.09. If the ODHS suspects that a doctor has not complied with the Act it will refer the matter to the Oregon Medical Board. In 2012 no referrals were made, but previous referrals have mainly concerned a failure to file documentation in a timely manner, or problems with the patient's written request, for example that the witness and patient did not sign the declaration at the same time as the patient. There is no independent commission in Oregon to evaluate the way in which the Act operates, or to advise on good practice, although guidance is issued by the Task Force to Improve the Care of Terminally-Ill Oregonians in *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*,<sup>118</sup> to which members of the ODHS contribute.

The Assisted Dying Bill 2013 provides that the Chief Medical Officers shall monitor the operation of the Act, including compliance with it and any codes of practice made under it,<sup>119</sup> but in the absence of a detailed reporting procedure there seems little scope for review. The only reporting requirements set out in the Bill relate to the recording of the death as an 'assisted death' on the death certificate.<sup>120</sup> Whilst such certification will allow the collection of statistics relating to the number of people assisted, the underlying terminal disease, age and gender, it is difficult to see how a death certificate will enable effective monitoring of assisted dying. In fact the only review of the attending doctor's decision-making and conduct foreseen by the Bill appears to be the independent consultant. As I have discussed above, SCEN-style

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<sup>118</sup> 2008, first edition 1998.

<sup>119</sup> Cl. 9(1) Assisted Dying Bill 2013.

<sup>120</sup> Cl. 7(2) Assisted Dying Bill 2013.

consultants may provide an effective a priori control mechanism,<sup>121</sup> however it seems unlikely that a sufficiently high level of oversight could be expected in a country where there are no experienced consultants in assisted dying, where there is no case law and as yet no professional guidance. Monitoring compliance with assisted dying is not a case where a ‘light touch’ approach should be adopted and this represents a key failing in the Bill.

It is suggested that the European model of establishing an independent multi-disciplinary monitoring commission/committees has much to recommend it, rather than delegating compliance monitoring to a government department, be it the Oregon Department of Health Services or the Department of Health. The review committees established by the Benelux countries are interdisciplinary and independent of the executive, they consider each case of assisted dying in detail and report to their respective Parliaments annually (in the Netherlands) or biennially (in Belgium and Luxemburg). The fact that the European model emphasises independent review agencies, separate from the state, underlines the fact that the review is separate from the criminal process. As Maurice Adams and Heleen Weyers have stressed, ‘What would previously have been an exclusively criminal assessment has now developed into a professionally and socially oriented assessment with the criminal law present only in the background.’<sup>122</sup> It is designed not only to ensure that doctors have complied with the law (cases of non-compliance are forwarded to the prosecution authorities), but also to gain an understanding of the way in which the law is operating on the ground, providing valuable feedback to individual doctors (in the case of problems), to the medical profession and general public (through information brochures designed to explain how the Acts operate) and to government through the reports evaluating the operation of the law.

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<sup>121</sup> J. Griffiths et al n.103, argue that increasingly consultations provided by SCEN doctors will constitute before the fact control, with RCCs functioning as a backup in difficult cases, at 139-140; M. Adams & H. Weyers “Supervision and Control in Euthanasia Law: Going Dutch?” (2012) 23 KLJ 121, at 133.

<sup>122</sup> *Ibid*, at 134.

The Dutch and Belgian committees approach monitoring compliance in a different way, but this article will concentrate upon the Dutch approach, recommending that it offers the best example of how a monitoring commission in England and Wales might monitor compliance, but also play an role in establishing good practice and evaluating the Act's operation.<sup>123</sup>

The Dutch report forms are very detailed, asking pertinent questions designed to allow the doctor to fully explain how she met the due care criteria and so allowing a high degree of scrutiny of the decision-making that led up to the decision to assist the patient to die. This allows the Dutch committees to give individual feedback to doctors, regardless of whether the due care criteria have been satisfied. The fact that the reports are so elaborate and thus time-consuming for the doctors to fill in, does increase the risk that doctors' willingness to report might be reduced, or that doctors might be more likely to withhold treatment or use palliative sedation instead of euthanasia to avoid the bureaucracy involved in reporting a termination of life. However, the information reported feeds into the Dutch annual reports which are informative and enable the commissions to develop and encourage good practice by publishing a number of case reports as part of the annual report, demonstrating examples of good practice and highlighting problem areas. Moreover, the annual reports create a significant degree of transparency in terms of how the committees operate and the criteria they apply in determining whether or not the doctor has complied with the due care criteria.

The reports produced by the OHSD and its Washington counterpart are of a very different nature to those produced by the European commissions, reflecting their different function and makeup. The American reports are drafted and issued by government agencies, rather than committees created specifically to monitor PAS. They are also much more limited in nature than their European counterparts, primarily reporting epidemiological data, and thus afford

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<sup>123</sup> For an excellent article discussing the differing approaches of the Belgian and Dutch Committees see T. Smets et al "The medical practice of euthanasia in Belgium and The Netherlands: Legal notification, control and evaluation procedures" (2009) 90 *Health Policy* 181.

no transparency, no opportunity to promote good practice, or even to identify whether the operation of the Act could be improved.

The Assisted Dying Bill's lack of provision for the establishment of a monitoring commission is particularly surprising given that the Assisted Dying Commission set out detailed plans for the functions to be performed by the monitoring commission – namely to monitor compliance, to publish information to inform and develop professional practice, to collect and publish national data and an annual report to Parliament and to encourage (and potentially fund) research on the process and consequences of introducing an assisted dying framework.<sup>124</sup> The failure of the Bill to provide for the creation of such an agency, with the obligation to produce annual reports similar to those produced by the Dutch RRCs is to be regretted and should be reviewed, particularly as it is suggested that the annual reports issued by the Dutch committees are an extremely important educational resource and play a great role in promoting good practice. Absent such an independent commission in England and Wales, the collection of statistics envisaged by the Bill is no more than an exercise in quantitative data collection, with means to assess the benefits and shortcomings of the Act and the context within which it operates, or indeed to improve the provision of end of life care.

### **III Concluding Remarks**

Any legislation designed to legalise assisted dying must establish the robust regulatory framework needed to ensure the protection of patients, but that requires the checks and balances contained in that legislation to be more than mere slogans of accountability, they must provide real accountability. The safeguards set out in the Assisted Dying Bill 2013 are reminiscent of what Michael Power terms 'ritualized practices of verification whose technical

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<sup>124</sup> Assisted Dying Commission Report, 2012, at 325.

efficacy is less significant than their role in the production of ... legitimacy.’<sup>125</sup> The strong upfront safeguards referred to by the Assisted Dying Commission cannot be reduced to the need to keep detailed records, where compliance is reduced to ticking off items on a checklist. Instead, the actors in the regulatory scheme, the attending and consulting doctors and an independent review commission charged with ensuring compliance, must seek to ensure that the strict confines of the law are respected, whilst not making access to assistance so burdensome as to be illusory. As Karen Yeung argues, policy makers should facilitate reasoned deliberation by those involved in the process,<sup>126</sup> in the present context this requires that all involved in the process, from the health care professionals involved, to the review committee charged with monitoring compliance, should seek to ensure that the substance of the legislation is given effect, not merely the form. A prime example of a body exceeding the rituals of verification is provided by the working methods and reporting style adopted by the Dutch RRCs who go beyond merely verifying compliance with the law, to play an educative role and promote good practice. As argued above, the role of the RRCs, and the manner in which they fulfil that role, are a key example of good practice that can usefully inform the policy debate in England and Wales.

Like the Oregon Death with Dignity Act upon which it is modelled, the Assisted Dying Bill 2013 effectively licences doctors to prescribe lethal medication in certain circumstances. It does not create a context within which the practice of assisted dying can be evaluated, or compliance monitored. In so doing it fails to take account of the wealth of good practice that exists within Europe, adopting a very pragmatic stance, artificially limiting its scope to apply to only the terminally ill and permitting only PAS. Both limitations are clearly attempts to assuage fears that legalisation may lead to abuse, but they disproportionately restrict the scope

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<sup>125</sup>M. Power *The Audit Society: Rituals of Verification*, Oxford: OUP, 1999, at 14; see generally chapter 6 ‘Audit, Trust, and Risk.’

<sup>126</sup>K. Yeung “Regulating Assisted Dying” (2012) 23 KLJ 163, at 170.

of the Bill, excluding many who would wish to seek assistance, who will be left to seek that assistance outside the regulatory scheme. Moreover, the promotion of universal human dignity indicates a need for confidence in the reporting and evaluation schemes put in place. It demands some way of holding doctors to account as they exercise the function of gatekeeper to assisted dying (ultimately the patient's choice is subject to a doctor being willing to assist her to die), and also a means of developing good practice and evaluating the operation of the legislative framework and the context within which it operates. In its current form the Bill provides none of these essential elements of a scheme designed to promote the dignity of the individual, whilst concurrently respecting the dignity of human life in general by effectively safeguarding the exercise of individual choice from abuse.

Whilst it is undoubtedly true that legalising assisted dying brings with it the potential for abuse, that potential already exists, as Emily Jackson argues, 'The argument that legalised assisted dying would represent a unique opportunity to mistreat the vulnerable is clearly misplaced.'<sup>127</sup> Individuals belonging to vulnerable groups are already disproportionately affected by paternalistic decision-making; the current legal context of end-of-life decision-making is neither ethically, nor intellectually consistent; and fears concerning the much criticised Liverpool Care Pathway<sup>128</sup> clearly demonstrate that there is a need for greater openness and understanding about choices available at the end-of-life, both in terms of what those choices are and who can make them. Moreover, as Clive Seale demonstrated, assisted dying is taking place,<sup>129</sup> but it takes place in an unregulated manner, with no supervision, no second opinions and no accountability. As Ronald Dworkin argued, the slippery slope

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<sup>127</sup> E. Jackson & J. Keown *Debating Euthanasia* Oxford: Hart, 2012, at 29.

<sup>128</sup> The government commissioned review of the LCP reported in July 2013, recommending that the LCP be phased out within 6 – 12 months and replaced 'by an end of life care plan for each patient, backed up by condition-specific good practice guidance.' *More care, less pathway: a review of the Liverpool Care Pathway*, 2013, at 48, available at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212450/Liverpool\\_Care\\_Pathway.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf), last accessed 02/09/2013.

<sup>129</sup> Above n.21.

argument ‘Loses its bite once we understand that legalising no euthanasia is itself harmful to many people, then we realise that doing our best to draw and maintain a defensible line, acknowledging and trying to guard against the risk that others will draw the lines differently in the future, is better than abandoning those people altogether.’<sup>130</sup>

It is clear that the absolute prohibition of assisted dying does not equate with legal control, but legalisation may bring wider benefits. For example, even if assistance were legally available, the evidence from Europe and America suggests that the take-up rate would be low, but the availability of assisted dying encourages greater openness and dialogue regarding end-of-life planning.. As Frances Norwood explains in her analysis of the Dutch experience, ‘in practice Dutch euthanasia is more often a discussion than it is a life-ending act - a discussion grounded in a cultural discourse that shapes how Dutch people come to think, feel and practice the end of life.’<sup>131</sup>

In summary, it is suggested that the time is certainly ripe for consideration of assisted dying, but for all the reasons given above, the Assisted Dying Bill 2013 needs significant amendment if it is to provide a robust framework within which assisted dying is to be available, promoting dignity at both the individual and community levels. A willingness to learn from the experience of our European neighbours and to site the provision of assistance in dying within the general context of end-of-life care is indicated in order to truly promote dignity and to respect and safeguard the value of all lives.

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<sup>130</sup> R. Dworkin n.31, at 197 – 8.

<sup>131</sup> F. Norwood *Euthanasia talk: Euthanasia discourse, general practice and end-of-life care in the Netherlands*. Ph.D. diss., University of California, Berkeley and San Francisco, 2005, at 11. Subsequently published as *The Maintenance of Life: Preventing Social Death through Euthanasia Talk and End-of-Life Care: Lessons from the Netherlands*, Durham: Carolina Academic Press, 2009.